

# Survey finds strokes of unknown cause leave patients and caregivers in the dark

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A patient and her physical therapist in a therapy session after stroke. Credit: copyright American Heart Association

According to a new survey from the American Heart Association/American Stroke Association, more than 50 percent of

stroke patients and caregivers report anxiety and frustration when the cause of the stroke was undetermined, or "cryptogenic." The survey, which included 309 cryptogenic stroke patients and caregivers, also found that only 20 percent of patients and caregivers report receiving information for cryptogenic stroke at the time of diagnosis.

The survey findings indicate that patients and caregivers are significantly impacted by [stroke](#) with more than 70 percent of both groups reporting feeling tired and drained (or having low energy) as a result.

Every year, about 800,000 Americans have a stroke. Of those, about 200,000 are considered "cryptogenic," meaning the cause of the stroke is undetermined. Statistics show [cryptogenic stroke](#) patients have reason to be concerned: A prior stroke is the number one risk factor for a second stroke.

Educating patients and families about cryptogenic stroke and diagnostic options will help manage feelings of worry, nervousness or unease and frustration they report from not knowing the cause of a stroke. This is why the American Stroke Association, with support from Medtronic, launched the Cryptogenic Stroke Initiative.

This month, the first Patient Guide to Cryptogenic Stroke is being released. The guide includes information on the cryptogenic stroke diagnosis, what happens during a stroke, secondary prevention information, questions to ask your doctor, support resources and more.

"Through the initiative, we're informing cryptogenic stroke patients about their condition and helping them to work with their healthcare team to prevent a second stroke," said Mary Ann Bauman, M.D., chair of the American Stroke Association Advisory Committee. "We know that focusing on these patients will help us save lives from stroke, which is the fifth leading cause of death in the U.S. and a leading cause of

severe, long-term disability."

The American Stroke Association's survey, which includes a combination of online and telephone interviews with 309 [stroke survivors](#) and caregivers, also provides insight into how cryptogenic stroke patients receive information about their diagnosis.

The survey reveals that only one in five patients receive information about cryptogenic stroke at the time of their diagnosis. Of patients receiving timely information, 75 percent received it verbally. Cryptogenic stroke patients and caregivers seek information from a variety of sources for the first year, but few report finding adequate information.

"It is extremely difficult to remember everything a doctor tells you when you're still trying to come to terms with the fact that you've had a stroke. We can help cryptogenic [stroke patients](#) and their families by providing comprehensive resources about the condition," Bauman said.

The association's Cryptogenic Stroke Initiative is designed to help patients like Bill Benedict, 79, from Ithaca, New York.

Benedict suffered two "mini-strokes" ([transient ischemic attacks](#) or TIAs) about a month apart. Each time, doctors were unable to give him a reason why they occurred. For Benedict, who has a personal history of heart trouble and a family history of stroke, this was far from reassuring.

"It was quite scary not to know," he said.

After his second [mini stroke](#), Benedict's cardiologist suggested an underlying cause may be atrial fibrillation (AF), which is a quivering or irregular heartbeat. AF often has no symptoms and comes and goes so it

may not always be detected by conventional cardiac monitoring techniques. While it can be tricky to diagnose, it's important because AF increases stroke risk up to five times.

His doctor agreed to test him for AF using a small, insertable device that monitors the heart rhythm continuously for up to three years. A few months after having it, the device detected [atrial fibrillation](#) and Benedict is now managing his condition through medication.

Although AF is one of the many likely causes of cryptogenic stroke, only 12 percent of patients were told that AF was a possible cause of their stroke. Other common causes for investigation include patent foramen ovale (PFO) a hole between the heart's chambers, and thrombophilia, a blood clotting disorder.

**More information:** To download the free Patient Guide or to learn more about cryptogenic stroke, call 1-888-4-STROKE (478-7653) or visit [www.StrokeAssociation.org/CS](http://www.StrokeAssociation.org/CS)

Provided by American Heart Association

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